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Inn Celebrates 25 Years of Helping Pediatric Patients

By Dana Talesnik and Eric Bock

Most parents would do almost anything to help their sick child. When children have rare, difficult to treat or undiagnosed conditions, they can be seen at the Clinical Center while they and their parents stay together at the Children's Inn at NIH.

Many call NIH the "National Institutes of Hope." The inn is a big reason for that title, explained NIH director Dr. Francis Collins at the inn's 25th anniversary symposium held recently in Masur Auditorium.



NCI's Dr. Lauren Wood moderated the anniversary event in Masur Auditorium.

The event celebrated the inn's role of assisting families who come to NIH for treatments that hold the prospect of improving the children's health and even curing their diseases.

Since 1990, inn CEO Jennie Lucca said, the inn has provided "a place like home" for nearly 13,000 families. Although it sits on government property, the inn is a nonprofit charity supported through private contributions. Besides offering a free place to

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Live Wires

Neurologist Tests Deep Brain Stimulation to Relieve Depression

By Dana Talesnik

When we feel sadness or grief, it's usually a passing phase. But what if you can't snap out of it? People with major depressive disorder often can't remember the last time, if ever, they had a good day. They're despondent, numb and disengaged because their anguish is immobilizing. Medicines, psychotherapy or other treatment might work for a time, but some chronically depressed patients don't respond long-term or at all to standard measures.

"So if you can't talk it, drug it or shock it, then go at it and modulate it," said Dr. Helen Mayberg, a neurologist and professor at Emory University School of Medicine, at a recent NIMH lecture at Porter Neuroscience Research Center. Mayberg, with a team of neurosurgeons, psychiatrists, psychotherapists, biomedical engineers and imaging scientists, has been pioneering research on deep

Content Syndication Helps Distribute Info Reliably, Quickly

By Eric Bock

During last fall's Ebola crisis, millions of users visited the NIH web site looking for reliable and current information about the disease. When the crisis began, most of the public health information offered by the federal government was on the Centers for Disease Control and Prevention's web site.

To keep the public informed, NIH pulled Ebola content directly from CDC's site. NIH could do this because CDC makes some of its content available to other sites through a process called content syndication.

"This is just one example of the benefits of content syndication," said Christen Geiler, a digital information specialist working with the OD Office of Communications and Public Liaison's Online Information Branch. "It's an easy and reliable way to distribute information. During the outbreak, it helped disseminate current and consistent messages about Ebola."

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NIH...Turning Discovery Into Health

briefs

Training Courses Available from EDI

The Office of Equity, Diversity, and Inclusion (EDI) offers a number of courses that satisfy your EEO mandatory training requirements. In addition to its popular EEO Training for Managers and Supervisors and EEO Training for Employees, EDI is rolling out new training modules focused on the prevention of workplace harassment. One module is specifically tailored to the needs of managers and supervisors; the other is designed for employees. Another course is SafeZone Training, a 3-part training to promote awareness and education about the needs and concerns of people who identify as lesbian, gay, bisexual, transgender and/or intersex (LGBTI) or sexual and gender minority populations (SGM).

Courses augment employees' knowledge and skill in the areas of EEO compliance, sexual harassment prevention, anti-discrimination, the prevention of workplace harassment and LGBTI/SGM inclusion. They also satisfy two mandatory training requirements (No FEAR Act and Prevention of Sexual Harassment) in one convenient session. In addition, participants have the opportunity to ask questions of knowledgeable equity, diversity and inclusion experts. Plus, managers and supervisors participating in EEO Compliance for Managers and Supervisors or Prevention of Workplace Harassment for Managers and Supervisors will receive 4 CLP credit hours.

To register for training, visit <http://edi.nih.gov/training/upcoming-training>. Note that classes with fewer than 15 registered participants will be cancelled 10 days prior to the class.

Anyone experiencing difficulty registering for the offerings should contact HR Systems Support at <http://intrahr.od.nih.gov/helpdeskform.htm>. Individuals who need reasonable accommodation to participate should contact Victoria Rucker, EDI training manager, at edi.training@nih.gov and/or the Federal Relay (1-800-877-8339). For additional questions, contact Rucker.

19th Annual Free Outdoor Film Festival

The 19th annual Comcast Film Festival will take place from Friday, Aug. 21 to Sunday, Aug. 23 at the MCPS Board of Education, 850 Hungerford Dr., Rockville. The format is drive-in, but you can also watch the free movies on the lawn; bring a blanket and low chairs. Films start at dusk.

There will be amusements and games, along with food and drinks available for purchase. There will also be a raffle and donations to help

raise funds for the NIH Charities (Friends of Patients at the NIH, the Children's Inn and Camp Fantastic/Special Love).

The featured films are:

Aug. 21 *How to Train Your Dragon 2* – PG

Aug. 22 *Interstellar* – PG-13

Aug. 23 *Guardians of the Galaxy* – PG-13



Surgeon General Pays Call on NIH

Surgeon general vice admiral Dr. Vivek Murthy (above, r) visited NIH for the first time on July 23, meeting NIH director Dr. Francis Collins and the institute and center directors and later speaking with members of the NIH Commissioned Corps in Wilson Hall. Among those welcoming the 19th U.S. surgeon general were RADM Helena Mishoe (below, c) of NHLBI and LT Jennifer Young of the Clinical Center's department of transfusion medicine.

PHOTOS: ERNIE BRANSON



nih record

Pérez-Stable To Direct NIMHD

Dr. Eliseo J. Pérez-Stable has been named director of the National Institute on Minority Health and Health Disparities. He is expected to join NIH in September.

“Eliseo is a highly respected leader with rich experience in advancing efforts to eliminate health disparities,” said NIH director Dr. Francis Collins, who made the appointment. “He has the passion and vision to guide the NIMHD research agenda in this critically important area.”

Pérez-Stable will oversee the institute’s \$270 million budget to conduct and support research, training, research capacity and infrastructure development, public education and information dissemination programs to improve minority health and reduce health disparities.

Pérez-Stable comes to NIH from the University of California, San Francisco, where he is a professor of medicine, chief of the division of general internal medicine and director of the Center for Aging in Diverse Communities. The center works to alleviate health disparities with a focus on improving health care for aging minority populations and to diversify the scientific workforce addressing these issues. He is also director of the UCSF Medical Effectiveness Research Center for Diverse Populations, which is addressing issues for African Americans, Asians and Latinos in the areas of cancer, cardiovascular disease and reproductive health.

Pérez-Stable’s personal research interest is in improving the health of poor and minority patients, reducing health risks such as smoking in minority populations and improving cross-cultural communication skills among health care professionals.

NIAID Study Seeks Women

NIAID is seeking healthy women, 18-40, for a research study to learn more about why antibiotics increase a woman’s risk of yeast infections. At least 7 outpatient visits take place at the Clinical Center. Compensation is provided. For more information contact the Office of Patient Recruitment, 1-866-444-2214 (TTY 1-866-411-1010). Refer to study 13-I-0181.



Northwest Child Care Center Moving Forward

The NIH Northwest Child Care Center (NWCCC) is once again moving forward after experiencing a delay during the design phase in 2014. This long-awaited facility will be situated on Center Drive, between the NIH Fire Station and the Children’s Inn, and will have capacity for up to 170 children between 6 weeks and 5 years of age. It will increase the overall volume of available child care spaces on campus while also providing a new home to the occupants of one of the smallest centers on campus.

The inception of this facility has been spearheaded by the Office of Research Services and the NIH child care board, in collaboration with the Office of Research Facilities, to address the increasing need for full-time child care to both attract and retain high-caliber employees at NIH. Funding was secured for the project but significant challenges in the planning and design phases have led to delays. The design is now being completed as part of a collaboration between many groups within NIH to address evolving requirements for issues ranging from security to environmental compliance.

The center will be environmentally forward in addressing stormwater concerns including the first installation of a pervious parking lot on campus, as well as a green roof and pervious sidewalk along the main pedestrian path adjacent to Center Drive. It meets not only Maryland state child care licensing requirements, but also will provide a warm and welcoming environment for the children of NIH families.

The NWCCC is anticipated to break ground this fall and will take about 1 year to complete. Once the contract is awarded for construction, expect to see additional fencing and project signage installed as well as sidewalk closures and intermittent traffic restrictions in the area. Due to the large volume of construction traffic during the early phases, it will be necessary to re-route pedestrian traffic for safety reasons. All efforts will be made to minimize the disturbance to the NIH community. The center is expected to open in spring 2017.

Further information is available from Tonya Lee, ORS child care programs manager, leet2@mail.nih.gov, or Stephanie Hixson, ORF project officer, hixsons@mail.nih.gov.



This is the south elevation of the new Northwest Child Care Center, due to debut on campus in spring 2017. Note the bell tower near the front door.

Dr. Helen Mayberg discovered that patients who recovered from depression always had down-regulation of a part of the brain called “area 25.”



MAYBERG

CONTINUED FROM PAGE 1

brain stimulation (DBS) to help clinically depressed, treatment-resistant patients.

DBS was first tested on patients with Parkinson's and other neurological and movement disorders. Mayberg deemed it a logical approach to treat depression, which can be modeled as a neurological disease. The technique involves a surgeon implanting electrodes connected by thin wires to a battery-powered pulse generator. For depression, DBS delivers a low-voltage current to a targeted region of the brain that regulates mood.

Mayberg's work builds on earlier research that showed regions of the brain in stroke patients where cognitive and motor components could be interrupted. By pinpointing where in the brain antidepressants, psychotherapy or other traditionally successful treatments act, they would target those areas. Mayberg discovered that patients who recovered from depression always had down-regulation of a part of the brain called subcallosal cingulate 25 or, simply, “area 25.”

But evolving data shows that other nearby areas can affect the larger network. Baseline scans can predict where in the brain to target and with what kind of treatment, Mayberg said, but “different treatments work on different components of the network and don't necessarily move it in the same direction.”

For example, part of the brain's cerebral cortex, the right anterior insula, is known to play a role in pain, addiction and anxiety. Research is currently under way to assess how modulating that region may play a role in selecting an optimal depression treatment.

Caught in a cycle of major discomfort and painful self-loathing, chronically depressed patients are stuck. One patient described the feeling as, “You can't get away from inside yourself to pay attention to anything else.” Mayberg's strategy is to map the negative mood directly. With major depression, the negative mood is so overpowering, the patient needs a reset to become unstuck, she said.

“This isn't just the absence of something; it's the presence of something bad that gets into a tug of war with your attempt to do something good,” said Mayberg. “It is a maladaptive state of a highly choreographed set of regions that are designed to mediate and disengage from pain—a poverty of willed action... as though it is this feedback system that's gone wrong.”

Mayberg's first DBS study starting in 2003 involved 6 patients with severe, recurrent major depressive disorder. Patients were implanted with bilateral stimulators in the white matter bordering area 25. After 6 months, she said, 4 of the 6 had shown improvement. The study expanded to 20 people, with a 64 percent response rate over 6 years.

At Emory, a second study included not only patients with major depression, but also patients with bipolar type 2 depression of comparable severity. Again, 40 percent of patients showed significant clinical improvement with 6 months of ongoing DBS. Notably, discontinuation whether by design or by a dysfunctional stimulator resulted in a loss of the antidepressant effects slowly over several weeks, which was reversed when the system was turned on or repaired.

Studies using diffusion tractography in these first 17 Emory patients have further demonstrated that non-responders can be converted to responders by adjusting stimulation parameters to impact the intersection of 4 white matter bundles that meet at area 25. Response rates using these refined new methods now exceed 70 percent in recent studies of 13 new patients.

While research teams continue to demonstrate sustained clinical response in more than 60 percent of implanted patients receiving DBS, other brain targets are also being investigated, said Mayberg, who reported exciting results across the board in non-blinded studies. Industry-sponsored trials, however, have been less successful; more research is needed to understand these different outcomes.

Interestingly, some patients with area 25 DBS have felt great relief immediately with initiation of acute stimulation in the operating room, suggesting several stages to the recovery process. But results have varied across individuals and have been hard to quantify. “What we may have missed is once you reset the system, you don't have a sense of how it's changing, so the idea of a linear gradation of recovery might not be right for this phenomena... We saw it in some patients, not all,” said Mayberg. “Everyone said something different.”

Mayberg's research team is now working to further refine the surgical procedure and stimulation algorithms to maximize benefit. Using MRI, they are tracing the pathways that mediate treatment response to do more targeted stimulation. And they're more precisely mapping white matter connections around area 25. Most recent studies suggest there are white matter abnormalities within these critical connections. With such abnormalities, said Mayberg, “You literally may not be able to receive or act on signals coming from the brain stem to effect a change at cortex or elsewhere. So when a patient says, ‘I can't get outside myself,’ they really can't.”

Thanks to new prototype devices to measure physiological changes in area 25 accompanying long-term recovery, her team has started to track the effects of chronic stimulation, extending studies beyond recordings in the operating room. Said Mayberg, “We need to refine the criteria for who we treat, where we implant and what we index or we're never going to have a trial that does anyone any good no matter how fancy our tools are.”

Burwell Recognizes NIH Innovation Awardees

The Health and Human Services IDEA Lab celebrated employee innovation and problem-solving at its eighth annual awards ceremony in Washington, D.C., recently. HHS Secretary Sylvia Burwell presented HHS Innovates Awards to seven teams, including two from NIH.

The first is NIH's Neuroimaging Informatics Tools and Resources Clearinghouse (NITRC). NITRC was credited with providing the "Biggest Bang for the Buck" in the competition, which drew 70 entries from across the department.

NITRC is a clearinghouse for data, software tools and other resources for researchers conducting functional and structural neuroimaging analysis. Researchers and the medical community use functional neuroimaging—such as magnetic resonance imaging (MRI) and electroencephalography—to measure aspects of brain function, including links between brain regions and specific mental processes or physical activities. They use structural neuroimaging—such as computerized axial tomography (CAT or CT) and MRI—to explore physical elements of the brain.

"A remarkable evolution in the development of neuroimaging tools and knowledge has taken place over the past half century," said Dr. Roderic Pettigrew, director of the National Institute of Biomedical Imaging and Bioengineering, which administers the NITRC project. "NITRC plays a very important role in cultivating a community of neuroimaging experts to advance our ability to visualize, study and understand intricate structures and circuits of the brain."

The NITRC web site, managed by a small business known as TCG, hosts a registry of neuroimaging tools and resources, an image repository for storing and sharing neuroimaging data and a computational environment that includes access to cloud computing. Among the hundreds of tools NIH offers through NITRC is a software package for reconstructing three-dimensional models of brain structures. Almost all of the software resources on NITRC are free, and all the data is free, fostering the exchange of ideas among users from U.S. universities, international organizations and virtual computing consortiums.

NITRC is funded by the NIH Blueprint for Neuroscience Research, a trans-NIH effort to accelerate the pace of discovery in neuroscience. The information technology firm TCG, which has developed and managed NITRC in collaboration



At the award ceremony are (from l) former NITRC project management leaders Michael Huerta, NLM, and James Luo, NHLBI; current NITRC project management leader Dr. Vinay Pai, NIBIB; HHS Secretary Sylvia Burwell; NITRC project manager Nina Preuss, TCG; David Cassidy, TCG vice president; and Dr. James Anderson, NIH deputy director for program coordination, planning and strategic initiatives.

with NIH since it first came online in 2006, estimates that the clearinghouse has provided more than \$35.3 million in potential savings by researchers accessing imaging data through NITRC.

The second NIH winner was the NIH 3D Print Exchange, also deemed a "Secretary's Pick." The exchange is an online portal to open-source data and tools for discovering, creating and sharing 3D-printable models related to biomedical science. Its goal is to empower researchers, physicians and the public with high-quality, informative models that inspire new discoveries that transform science and health care.

Less than 10 months from its public launch, the exchange has grown to include more than 2,000 registered users and more than 5,000 3D models. As the first federal government web site dedicated to 3D printing, it is engaging with other agencies to facilitate sharing of digital 3D data. The entire site is built on an open source platform, making it fully scalable and transferable.

3D printing is transforming medicine through enhanced surgical planning and affordable, custom prosthetics. In the laboratory, 3D prints are saving thousands in research funding through improved efficiency. Most importantly, 3D-printed models can reveal valuable insights into complex structures and concepts. By stimulating greater adoption of 3D printing in bioscience, the NIH 3D Print Exchange is inspiring new innovation and discoveries that can ultimately advance scientific understanding and patient care. 1

People with TBI Needed for Study

The Clinical Center is seeking people who have experienced a traumatic brain injury (TBI) to participate in an outpatient research study. Researchers are testing whether two different types of exercise programs have an effect on mental and physical function in people who have TBI. Study procedures and exercise sessions take place at the Clinical Center. Study-related tests are provided at no cost. Compensation will be provided. For more information, call the Office of Patient Recruitment, 1-866-444-2214 (TTY 1-866-411-1010). Refer to study 15-CC-0164.



ANNIVERSARY

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Above, from 1:

Dr. Crystal Mackall, chief of pediatric oncology at NCI, said the inn is vital for observing the effects of treatments over time.

Kathe Barchus (l), her 11-year-old son Isaac and Dr. Raphaela Goldbach-Mansky of NIAMS talk about Isaac's rare autoinflammatory disease and how the Children's Inn eased the burden during his frequent visits to NIH for treatment.

PHOTOS: ERNIE BRANSON

stay, the inn presents residents with a range of therapeutic, recreational and educational programs and services.

"We do everything we can to provide a complete sense of respite," Lucca said. "We want to make sure these families feel safe, cared for and supported."

CC director Dr. John Gallin recounted the "awful conditions" families faced before the inn opened. As a young NIH physician in the 1970s, he regularly saw families sleeping in their cars or in hospital waiting rooms. The only food they ate came from vending machines. Those who stayed in hotels did so at their own expense. Among parents facing such stress, divorce was common.

The idea for an inn came from Dr. Philip Pizzo, who was then chief of pediatric oncology at NCI. He told Gallin about his vision of a home-like environment where families could take refuge from the hardships accompanying treatment of oftentimes gravely ill children. Determined to succeed, Pizzo, with the help of congressional leadership and private industry, eventually made his vision a reality.

"The Clinical Center cares for a child's medical needs," said Gallin. "The inn tends to a child's heart, soul, spirit and family."

Dr. Lauren Wood, head of the NCI Vaccine Branch clinical trials team, moderated a panel of three NIH investigators and three young patients who were returned to health through experimental treatments, compassion and years of persistence.

"It's the ultimate professional reward of your life's work to see your patients restored to health," said Wood.

Robert Harding, now 25, came to NIH 20 years ago with a serious liver infection, a complication from his chronic granulomatous disease, an immune system disorder. Amanda Lee, 20, came to NIH 3 years ago with synovial sarcoma, a rare form of cancer.

Harding and Lee hadn't responded to standard treatments elsewhere so they took a chance on NIH clinical trials, a decision that paid off for both. Dr. Steven Holland, chief of NIAID's Laboratory of Clinical Infectious Diseases, who treated Harding and still monitors his progress, beamed about watching him grow from a young child who hated getting his belly examined to a young man about to enter the police academy.

"I keep coming back because of Dr. Holland," said Harding. "He saved my life."

Dr. Crystal Mackall, chief of pediatric oncology at NCI, who treated Lee, said the inn is vital for observing the effects of treatments over many weeks, especially given the toxicity of some therapies.

"The fact that [children and young adults] can live at the inn during that time and have a home away from home, get caring and develop community with other people going through similar experiences...makes all the difference in the world," Mackall said.

Isaac, 11, has been sick since he was 2 weeks old and has come to NIH regularly since age 2. It took 7 years of trial and error before his doctors could identify the reason for his rare autoinflammatory disease called CANDLE. In Isaac's case, his immune system wouldn't shut off and was attacking his body's healthy cells, causing him to suffer fevers, rashes and joint pain, said Dr. Raphaela Goldbach-Mansky, acting chief of the translation-



Inn CEO Jennie Lucca said the inn has provided “a place like home” for nearly 13,000 families.

al autoinflammatory disease section, NIAMS.

“The Children’s Inn was a blessing because [NIH] is so huge; we were overwhelmed,” said Isaac’s mother Kathe. “[It was wonderful] to be able to go back to the inn at night and know that it was welcoming and inviting. We could have something to eat and relax and talk to someone else who knew what our path was. We could have spiritual help and guidance with other families.”

The inn helps alleviate the fears and frustrations of exams and treatment, offering both a refuge and a bustling community. Young patients enjoy playing video games and bingo, having family dinners and taking group trips to the circus or sporting events. There are also “thoughtful treasures”—donated toys or other surprises left in each child’s mailbox daily.

Isaac said he always looks forward to socializing at the inn after a long day at the CC. Amanda recounted that, while undergoing immunotherapy at the CC, her window faced the inn, which motivated her to get through the day so she could return there.

The inn empowers the work of NIH researchers and continues to “evolve and grow to support their needs,” said Lucca. The inn also has resources to allow patients to continue long-term protocols.

The Children’s Inn-Clinical Center partnership fulfills a critical need to study diseases from infancy to adulthood. Inflammatory diseases in children are chronic and often last a lifetime, said Goldbach-Mansky; it’s important to assess the long-term effects of treatments. Research is under way to explore whether drugs used in rare children’s syndromes could also help adults.

Investigators said they welcome the opportunity to follow patients for many years after recovery. Holland also lauded the opportunity to study interrelated conditions and symptoms. “Many times, we’ve found [health problems] that turn out all to be unified together in the condition the patients have. Precisely being able to do that here is unique and exquisite.”

In his keynote address, Collins said scientists have discovered the genetic basis for some 5,500 diseases since the Human Genome Project was completed in 2003. While this is encouraging, he noted, so far only about 500 of these diseases have treatments.

“It’s a very difficult and long process to go from knowing a molecular cause to coming up with an intervention—whether it’s a drug or some other kind of therapeutic,” he said.

He said the National Center for Advancing Translational Sciences and other ICs are committed to accelerating the development of new treatments and even

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Ben Banks: A Patient’s Story

A bubbly, giggly toddler named Finley ran up and down the aisle in Masur Auditorium during the 25th anniversary of the Children’s Inn at NIH. Finley is a healthy 2-year-old whose dad, Ben Banks, was her age when he was diagnosed with advanced cancer.

Speaking at the inn symposium, Banks said doctors once told his parents it would be miraculous if their 2-year-old son survived surgery. He had stage 5 bilateral Wilms’ tumors on both kidneys and the cancer had spread to his lungs. While still a toddler, Banks would endure two surgeries, three blood transfusions and serious side effects from 15 months of chemotherapy and radiation. It was a miracle he survived. Over time, he gained strength and recovered.

But at age 12, while celebrating 10 years cancer-free, a routine checkup revealed devastating news: Banks was HIV-positive. “So here I had to face the fact that one of my blood transfusions I received



Ben Banks, now 36, stays involved at the inn as a volunteer and participates in long-term follow-up and other clinical studies.

that saved my life from cancer was tainted with HIV,” said an emotional Banks. “I immediately froze, went numb and collapsed into my mother’s arms.”

Little was known about childhood HIV back in 1991. A pediatric infectious disease specialist at Bethesda Naval Hospital put Banks on the antiretroviral drug AZT. Soon after, Banks arrived at NIH.

His mother enrolled him in the first interleukin-2 protocol, a grueling regimen that tested his strength and spirits. During his treatments, Banks stayed at the Children’s Inn.

While there, he became friends with kids of all ages from around the world and said he loved the camaraderie and diversity of the inn. He fondly remembers time spent in the game room and the daily gifts waiting in his mailbox, donated by generous patrons.

Banks, now 36, stays involved at the inn as a volunteer and participates in long-term follow-up and other clinical studies. In 2013, a sperm-washing procedure along with artificial insemination allowed his wife Kasiah to give birth to their HIV-free daughter, Finley.

Banks remains grateful to the Children’s Inn. “There was always someone there to take away the stress from the day,” he said. “There’s so much love and care that goes into that place...The inn provided me with hope for the future.”—Dana Talesnik



Above:

Amanda Lee (l) and Robert Harding (r), who came to NIH with rare diseases, listen as Dr. Steven Holland of NIAID talks about following the progress of young patients to gain a better understanding of a range of diseases.

Below:

Isaac and Goldbach-Mansky pause for a photo.



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repurposing approved drugs to sidestep the time-consuming process of drug development and safety testing.

Collins told the story of Kayla Martinez, a patient with neonatal-onset multisystem inflammatory disease, an often-fatal rare illness that causes chronic inflammation. At NIH, her doctors discovered the disease's genetic mutation and wanted to test an anti-inflammatory drug that was already approved to treat rheumatoid arthritis. Kayla was one of the first patients enrolled in a clinical trial testing this drug and her condition improved dramatically.

"That's the kind of thing we'll be continually looking for in the future—how to shortcut this process," Collins said.

In all his time at NIH, Collins said, he "couldn't remember a day that was more powerful" than when he joined U2 guitarist The Edge and three young CC patients—Lauren Weller, Nachiketa "Nachu" Bhatnagar and Andrew Windland—for a U2 concert at Baltimore's M&T Bank Stadium. Before the show, The Edge invited the youngsters onstage to play his guitar.

All three were undergoing rigorous chemotherapy at the time, but "for a few hours none of that seemed to matter so much. They were there as guests of the guitarist who leads U2 and they were having a ball," Collins said.

Sadly, all three since have passed away. Collins said such disappointments drive both himself and other researchers to discover treatments that will work "the next time and the time after that and the time after that.

"Lauren, Nachu and Andrew—they're heroes, they're our partners and part of our family," he concluded. "They were then and they are now. They are what makes this place special. They were willing to put their trust and faith in the Clinical Center and the Children's Inn to try and see if something can be done—if not for them, then for others after them." 🕯



NINR director Dr. Patricia Grady (front, second from r) with center directors and NINR staff

NINR Hosts Center Directors Meeting

The National Institute of Nursing Research recently hosted a meeting of the directors of NINR-funded P20 and P30 centers to identify collaborative opportunities to advance nursing science. The centers focus on key research areas such as self-management and symptom science including sleep, pain and brain biology.

NINR director Dr. Patricia Grady highlighted the increasingly critical roles that team science and big data have in advancing health and health care.

"Just as nursing science encourages cross-disciplinary collaboration within and between universities and health science centers, I wish to stress the added power that can be obtained through the sharing of data across our centers through the use of common data elements," Grady said. "The more we can enhance and utilize our research data, the more we can leverage science to enhance quality of care, improve patient outcome and inform policy."

The meeting's keynote speaker was Dr. Ann Bonham, chief scientific officer of the Association of American Medical Colleges. She addressed the unique perspective that transdisciplinary team science brings to furthering translational data science and improving health and health care.

The day's meeting had various panel discussions, breakout sessions and poster sessions that provided an opportunity for the centers to share their unique strengths and accomplishments.

Grady concluded, "The Centers Program is an important part of NINR's research portfolio. The centers you lead provide research capacity that builds the evidence base for translating research into practice and policy to improve the health of all."

digest



Infants should be placed to sleep alone, on their backs, on a firm sleep surface, such as on a mattress in a safety-approved crib, covered by a fitted sheet. Soft objects, toys, crib bumpers, quilts, comforters and loose bedding should be kept out of the baby's sleep area.

PHOTO: SAFE TO SLEEP CAMPAIGN

Many New Moms Report No Physician Advice On Infant Sleep Position, Breastfeeding

Many new mothers do not receive advice from physicians on aspects of infant care such as sleep position, breastfeeding, immunization and pacifier use, according to a study funded by NIH.

Health care practitioner groups have issued recommendations and guidelines on all these aspects of infant care, based on research that has found that certain practices can prevent disease and even save lives.

The study authors surveyed a nationally representative sample of more than 1,000 new mothers, inquiring about infant care advice they received from doctors, nurses, family members and the news media.

Roughly 20 percent of mothers said they did not receive advice from their doctors regard-

ing current recommendations on breastfeeding or on placing infants to sleep on their backs—a practice long proven to reduce the risk of sudden infant death syndrome. More than 50 percent of mothers reported they received no advice on where their infants should sleep. Room-sharing with parents—but not bed-sharing—is the recommended practice for safe infant sleep.

The study appeared in *Pediatrics* and was conducted by researchers at Boston Medical Center, Boston University and Yale University.

Gene Variant Linked to Compulsive Drinking

Carrying a gene variant that affects the release of a specific brain protein may put one at greater risk of developing an alcohol use disorder, according to the results of a recent animal study. The study, published in *Biological Psychiatry*, was funded by NIAAA.

Scientists found that mice carrying the Met68BDNF gene variant, which reduces the release of brain-derived neurotrophic (BDNF) factor, would consume excessive amounts of alcohol, despite negative consequences. BDNF plays a role in the survival of existing neurons and the growth of new neurons and synapses, the junctures through which cell-to-cell communication occurs. The human form of this gene variant, Met66BDNF, leads to a reduction in the normal function of BDNF in the brain and is associated with several psychiatric disorders, including schizophrenia and depression.

In an animal study reported earlier this year, NIAAA-supported scientists found that adolescent binge drinking was linked to lower levels of brain-derived neurotrophic factor; these changes persisted into adulthood.

“Genetic factors play a role in determining who develops alcohol problems,” said Dr. George Koob, NIAAA director. “By understanding the genetic underpinnings of alcohol use disorder, we will be better able to develop targeted treatment and prevention strategies.”

Alcohol use disorder affects about 16.6 million adults in the United States.

Knowing whether patients carry a gene that results in decreased BDNF function could help in tailoring alcohol prevention and treatment strategies in the future.

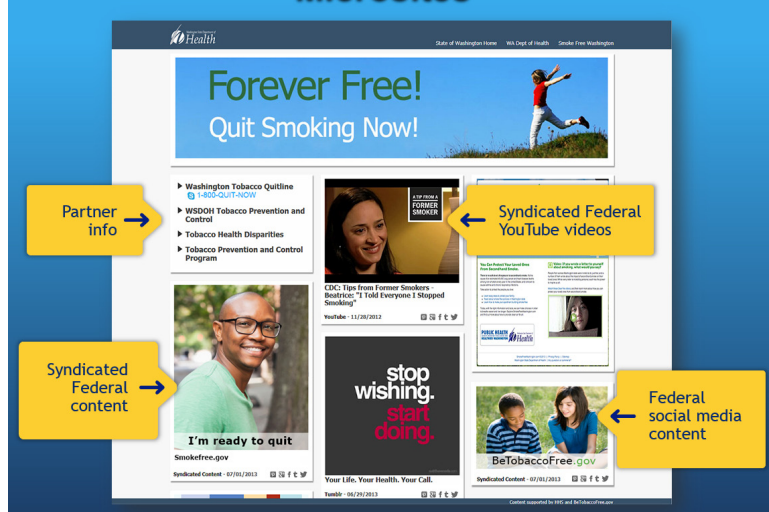
HIV Control Through Treatment Durably Prevents Heterosexual Transmission Of Virus

Antiretroviral treatment that consistently suppresses HIV is highly effective at preventing sexual transmission of the virus in heterosexual couples where one person is HIV-infected and the other is not, investigators reported at the 8th International AIDS Society Conference on HIV Pathogenesis, Treatment & Prevention in Vancouver. The finding comes from the decade-long HPTN 052 clinical trial funded primarily by NIAID and conducted by the NIH-funded HIV Prevention Trials Network (HPTN).

In 2011, HPTN 052 study investigators reported a breakthrough: Starting HIV treatment early, when the immune system is relatively healthy, reduced the risk of sexually transmitting the virus to an uninfected partner by 96 percent over 18 months. Based on additional data gathered since 2011, the recent finding unequivocally demonstrates the enduring power of HIV-controlling antiretroviral therapy to greatly reduce sexual transmission of the virus.

“The study now makes crystal clear that when an HIV-infected person takes antiretroviral therapy that keeps the virus suppressed, the treatment is highly effective at preventing sexual transmission of HIV to an uninfected heterosexual partner,” said NIAID director Dr. Anthony Fauci. “For heterosexuals who can achieve and maintain viral suppression, the risk to their partners is exceedingly low.”

Microsites



Syndication allows NIH's science-based resources to be combined with information at state and local levels and helps coordinate health messaging for maximum impact.

milestones



Dr. Jack Whitescarver (l), shown here with Ambassador Eric Goosby at an international AIDS conference, recently retired from NIH.

OAR Leadership Team Steps Down Whitescarver, Wertheimer Retire

NIH associate director for AIDS research Dr. Jack Whitescarver, who directed the Office of AIDS Research (OAR), and Wendy Wertheimer, OAR senior advisor, have both retired from their long-held positions.

Whitescarver had served in OAR since its establishment in 1988, first as deputy director and then as director from 2002 to 2015. Under his leadership, OAR implemented annual planning, budgeting and portfolio assessment processes that made the AIDS research program a unique model of trans-NIH coordination and collaboration involving every institute and center.

Recently, Whitescarver led a year-long process involving AIDS experts from around the world to reaffirm the highest priorities in AIDS research and conduct a review of the entire AIDS portfolio. He launched innovative international and domestic research and training programs, particularly addressing women and minorities as well as programs to assist and mentor early career investigators.

With Nobel laureate Prof. Francoise Barre-Sinoussi, he serves as co-chair of the International AIDS Society (IAS) "Towards an HIV Cure" advisory board. Whitescarver was the first recipient of the IAS Presidential Award for outstanding commitment to the global fight against HIV and pioneering work in the field.

His retirement caps a long career at NIH. In 1977, Whitescarver completed the Grants Associates Program and became special assis-

SYNDICATION CONTINUED FROM PAGE 1

Whenever CDC updated its content, the NIH information automatically updated as well. There wasn't any conflicting information about the disease, she noted, because both agencies used the same information.

"It's important for us to start thinking about our content beyond the confines of our own web sites," said Scott Prince, chief of the Online Information Branch. "By offering structured content, we can expand our reach exponentially. Content syndication is a great example of this."

Those using syndicated content have access to information vetted by experts that they otherwise wouldn't have, Geiler explained. Also, because syndicated content is updated automatically, it requires no maintenance. Staff can devote their time to other priorities, saving time and money.

"Syndication allows our science-based resources to be combined with information at state and local levels and it helps coordinate health messaging for maximum impact," she said.

Geiler added that content syndication remains unbranded to a particular agency, so it fits in seamlessly on NIH's site. NIH was able to customize its Ebola content so that it matched the design of NIH's other web pages. The site also included links to recent press releases about Ebola.

"Offering your content through syndication is simple," said Geiler. "More than half of the institutes and centers now offer or are planning to offer their web content for syndication."

Content that can be syndicated includes health information, images, videos, podcasts and data sets. ICs can provide their content on an online "Department of Health and Human Services Syndication Storefront," a marketplace listing all content available for syndication. NIH content would then appear on the storefront, along with content from HHS, the Food and Drug Administration and CDC.

Once it's on the storefront, other federal agencies, state and local governments, members of the public and businesses can download the content and post it on their own sites. The Office of Extramural Research will soon be offering grant funding information on the storefront.

"This will be helpful, for example, for a university that employs researchers who rely on grant funding," Geiler explained. "The university can place information about NIH grants directly onto its web site and have it update automatically when there is a change," she said.

Currently, Geiler is working with many ICs to place more content on the storefront. For more information, contact her at Syndication@nih.gov. 

tant to then-NIAID director Dr. Richard Krause. During this time, Whitescarver participated in development of the initial federal response to address the emergence of the new infectious disease now known as AIDS. From 1984 to 1988, he held positions as associate dean for research development and assistant professor of pathology at Emory University School of Medicine.

Wertheimer has served with Whitescarver as senior advisor in OAR since 1992. She first met Whitescarver and Krause in 1977, when she was a legislative assistant to Sen. Jacob Javits, the ranking member of the Senate authorizing committee. There she had responsibility for NIH authorization and legislation on women's health, sexually transmitted diseases and genetic diseases. She next served as deputy executive director of the American Social Health Association, where she was one of the first AIDS advocates and led the establishment of the National AIDS Hotline.

Wertheimer served as special assistant to Dr. Jonathan Mann, director of the Global Programme on AIDS at the World Health Organization in Geneva, Switzerland. She was recruited to NIH in 1991 by Dr. Ruth Kirschstein to assist her in establishing the NIH Office of Research on Women's Health.

As senior advisor to the OAR director, Wertheimer has been responsible for policy, planning, legislation and communications.

Wertheimer and Whitescarver enjoyed a unique and productive professional partnership that has spanned nearly four decades. They have devoted their careers to the field of AIDS and are both committed to continuing this work in new capacities outside of NIH.



At a White House reception, recording artist Annie Lennox (l) chats with Wendy Wertheimer, who retired recently as senior advisor in NIH's Office of AIDS Research.



Acting NCI director Dr. Doug Lowy (third from l) welcomes new NCAB members. They are (from l) Drs. Timothy Ley, Peter Adamson, Max Wicha, Tyler Jacks and Deborah Bruner; at right is Dr. Yuan Chang.



White House Announces New NCAB Members

The White House has announced the appointment of five new members to the National Cancer Advisory Board and the redesignation of NCAB chairperson Dr. Tyler Jacks.


Jacks is director of the Koch Institute for Integrative Cancer Research and David H. Koch professor of biology at the Massachusetts Institute of Technology. He has pioneered the use of technology to study cancer-associated genes and to construct animal models of many human cancer types, including cancers of the lung, pancreas, brain and ovaries.

Dr. Peter C. Adamson is chair of the international Children's Oncology Group and professor of pediatrics and pharmacology at the University of Pennsylvania School of Medicine. He is an internationally recognized leader in pediatric cancer drug development.

Dr. Deborah Watkins Bruner is the Robert W. Woodruff chair of nursing at the Nell Hodgson Woodruff School of Nursing, Emory University, and associate director for outcomes research at Emory's Winship Cancer Institute. She has a strong background in behavioral sciences, including quality of life in cancer patients.

Dr. Yuan Chang is American Cancer Society research professor, distinguished professor of pathology, department of pathology and UPMC endowed chair in cancer virology at the University of Pittsburgh Cancer Institute. Her specialties include viral oncology, cell biology, KSHV/HHV8 epidemiology, biology and tumor virology.

Dr. Timothy J. Ley is the Lewis T. and Rosalind B. Apple professor of oncology in the department of medicine and director of the stem cell biology section in the division of oncology at Washington University School of Medicine. He is a hematologist, oncologist and cancer biologist as well as an internationally known expert in the pathogenesis of acute myeloid leukemia and other blood-related disorders.

Dr. Max S. Wicha is Madeline and Sidney Forbes professor of oncology at the University of Michigan Comprehensive Cancer Center and deputy director of the A. Alfred Taubman Medical Research Institute. He is nationally known for his research in the field of breast oncology, particularly the study of how breast cancer cells grow and metastasize. 



An architectural rendering of the finished bridge

New Northeast Bridge Construction Complete

On Aug. 2, 2010, two Office of Research Facilities employees, Tony Chestang and Joe Jackson, were performing routine campus site inspections and discovered structural concerns with the existing “Northeast” bridge servicing North Drive off of Rockville Pike.

Over 30 years, the previously wooden-decked bridge had been replaced with metal decking. Reinforced concrete slab and decorative stone walls had been placed at the outer edges of the bridge.

The two employees discovered that the south girders—supports that raise the bridge off the ground—were damaged. The cantilever used to help support the bridge was sagging and the metal and concrete decking was starting to leak.

Chestang immediately contacted his supervisor, Paul Hawver, and all traffic was stopped from crossing the bridge. ORF senior structural engineer John Pavlides was called in to further study the bridge. Following his initial assessment, a decision was made to block off the south portion of the bridge, allow traffic to use the north portion and begin the procurement process to repair or replace the bridge.

In April 2011, under the direction of ORF’s Marjorie Marcus, NIH hired a firm to conduct a preliminary assessment of the bridge. The study’s result included 6 options for repair or replacement ranging in lifespan, types of materials used and locations for a new bridge. Options included everything from a short-term repair lasting 5 to 8 years, all the way up to long-term replacement lasting at least 50 years. NIH chose the long-term option—a bridge designed to hold for at least 50 years made out of precast concrete and located in the same place as the existing bridge.

By November 2014, the final design was completed by Howard Leroy Shrodes/Paige Industrial Services (HLS-Paige) Joint Venture. The design called for an approximate quarter-acre two-lane concrete bridge, 50 feet long by 30 feet wide, with protective “parapet” retaining walls faced with natural stones on both sides and supported by two concrete abutments at each end. The project also called for replacement of electrical conduit and communication lines, embedding them inside the bridge. Lenin Andrade was named ORF project officer overseeing construction of what became known as the North Bridge Replacement Project.

The contract was awarded to HLS-Paige Joint Venture and construction began in January 2015. Quality control, quality assurance and daily site inspections by the AFG Group have assured that the project adheres to all local, state and federal codes, especially requirements for sediment and erosion control, as the bridge is built over a stream that feeds into Rock Creek and contains marine life and occasional waterfowl. The bridge meets American Association of State Highway Officials design standards, capable of handling up to an 85,000-pound loading capacity and large emergency vehicles.

Initially, the bridge was set to open on Sept. 30. However, construction moved ahead of schedule. The new bridge debuted Aug. 10.

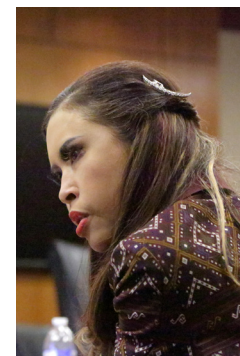


Thai Princess Makes 3-Day Visit to NIH

Her Royal Highness Princess Professor Chulabhorn of Thailand (at right, above) returned to NIH July 20-22 to visit NCI facilities in Frederick, Ft. Detrick and Bldg. 31, where acting NCI director Dr. Douglas Lowy and other NCI officials offered overviews of cancer precision medicine, cancer genomics projects and population studies.

Chulabhorn, who holds a Ph.D. in chemistry and has long been interested in natural products as potential therapies, has visited NIH periodically since the late 1980s. She established the Chulabhorn Research Institute in 1987 in honor of the 60th birthday of her father, King Bhumibol.

PHOTOS: ERNIE BRANSON



NIDA Director Keynotes Conference

NIDA director Dr. Nora Volkow (c) recently delivered the opening keynote at the 8th International AIDS Society (IAS) Conference in Vancouver. The conference on HIV pathogenesis, treatment and prevention is the world’s leading scientific meeting on HIV. Volkow presented on the topic “Injection Drug Users and HIV” to more than 6,000 attendees. She told the audience how drugs have contributed to the HIV epidemic and spoke of the importance of integrating HIV and addiction treatment. Joining Volkow are Dr. Julio Montaner (l), director of the British Columbia Centre for Excellence in HIV/AIDS, and Dr. Chris Beyrer, IAS president.